Assessment of the Perceived Role and Function of a Community Advisory Board in a NIH Center of Excellence: Lessons Learned

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Abstract

Background: The Community Advisory Board (CAB) was a vital component of the Center for Equal Health. The center addressed health disparities through community-based research and educational outreach initiatives. Objectives: To evaluate the perceived relationship of the CAB and Center, explore members' perceptions of the CAB's role, and elicit feedback on how to enhance the relationship between the Center and the CAB. Methods: Ten in-depth, semi-structured interviews were conducted. All interviews were transcribed verbatim and analyzed with a focus on predetermined codes. Results: Main themes focused on perception of CAB roles and need for utilization of board members; overall center challenges; and board member knowledge and communication within the center. Conclusions: Lessons learned mainly focused on clarification of CAB roles as necessary for more effective and efficient communication. Based on feedback, communication channels between the board and center were developed, orientation packets clarifying center roles were provided, and annual retreats were completed. Additional lessons learned for conducting community-academic partnerships are provided.

Keywords

Community advisory board; community-academic partnership; evaluation; community research; health disparities

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ABSTRACT

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INTRODUCTION

The Center for Equal Health (CEH), a National Institute on Minority Health and Health Disparities (NCMHD) Center of Excellence, was a collaborative research effort involving the University of South Florida and the Moffitt Cancer Center, a National Cancer Institute (NCI) Comprehensive Cancer Center from 2009-2014. CEH conducted studies and promoted activities to reduce cancer health disparities among minority and undeserved communities in the state of Florida (Green et al., 2013). The studies and activities of CEH have been described in detail elsewhere (Green et al. 2013). According to the National Institutes of Health (NIH), health disparities are differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States (Mitchell et. al, 2006; National Institute of Health, 2014; National Cancer Institute, 2008). These differences stem from many different social determinants of health, including poverty, racial and ethnic discrimination, and living in low socio-economic neighborhoods (Mitchell et. al, 2006; National Institute of Health, 2014; National Cancer Institute, 2008; American Cancer Society, 2009). Health disparities place a burden not only on our health care system, but more importantly on individuals, families and communities (National Cancer Institute, 2008; American Cancer Society, 2009). CEH addressed health disparities by creating community-based and driven research and education.

As detailed previously in Green et al. (2013), CEH was comprised of four main cores: administrative, research, research training and education, and community engagement and outreach. The administrative core provided oversight, coordination, and monitoring for each core and provided support and direction for all Center participants. The research core connected and oversaw the research activities, as well as fostered and supported new projects throughout the center. The research training and education core developed competent, well-trained minority researchers and healthcare professionals who would be prepared to effectively address cancer disparities in the state of Florida and around the nation through transdisciplinary research. And lastly, the community engagement and outreach core strengthened, enhanced and expanded meaningful community-academic partnerships that positively impacted health disparities through innovative community awareness and outreach activities. An additional aim for the Community Engagement and Outreach Core (CEOC) was to improve the coordination and communication between communities, institutions and researchers.

Background

Newman et al. (2011) define the purpose of a Community Advisory Board (CAB) as "an infrastructure for community members to voice concerns and priorities that otherwise might not enter into the researchers' agenda, and advise about suitable research processes that are respectful of and acceptable to the community" (p. 1). Further, they place importance on "assessing the roles, responsibilities, and processes of CABs" to assist in the building and supporting of "mutually beneficial partnerships between academic researchers and communities" (Newman et al., 2011, p.1).

The CAB was an important component of CEH, in that it served to link CEH to the community. CAB members were critical to ensuring that the CEH thoroughly engaged the community and increased community capacity. The CAB was designed to provide input, advice, and insight to the CEH faculty and staff regarding the health needs of the community (Green et al., 2013). Additionally, the CAB acted as a sounding board for CEH on new opportunities and challenges, and provided a community perspective on research activities. The CAB consisted of

19 members representing faith-based organizations, state and county health departments, local businesses, community-based organizations, and political leaders. The CAB participated in monthly meetings, alternating between face-to-face and conference call meetings. The CAB also attended the annual External Advisory Board meeting. Additionally, one CAB member served on the review committee for the Center's multiple research projects.

To create a robust infrastructure that engages community and academic partners through meaningful collaborations, at the end of the second year the CEOC conducted interviews with CAB members to: 1) evaluate the perceived relationship of the CAB and the CEH, 2) explore members' perceptions of the CAB's role, and 3) elicit feedback on how to enhance the relationship between the CEH and the CAB. Furthermore, the study was an opportunity to explore how CAB members perceived their role within CEH and how, if necessary, to enhance their collaboration.

METHODS

At the time of the interviews, there were nineteen CAB members. Using purposive sampling, all CAB members were asked to participate in the study; only ten met the inclusion criteria of having participated in at least one CAB meeting within the previous year. Participants were recruited through an email solicitation, followed by an announcement at a CAB meeting. A total of 10 in-depth interviews were conducted with active CAB members. Participants were affiliated with the Florida Department of Health (n=2), local family health centers (n=3), and community-based organizations (n=5). Three participants were male and the rest were female.

After the study received Institutional Review Board approval, telephone interviews were conducted individually by two of the authors and lasted between 30-45 minutes. Each interview was audiorecorded. Using a grounded theory approach (Glaser & Strauss, 1967), the interview guide was developed by one of the authors and focused on five categories of interest: Role and Participation; Current State of the CAB: Structure, Function, Role; Relationship between the Cores and the CAB; Future Suggestions; and Closing Comments. Structurally, the five categories in the interview instrument mirrored the guidelines set by George et al. (1999). The content of each category primarily corresponded with the measurable characteristics of "Group Dynamics Characteristics of Effective Partnership," but also included "Environmental Characteristics," "Structural Characteristics," and "Intermediate Measures of Partnership Effectiveness" (George, Daniel & Green, 1999). Throughout the interview process, member checks were conducted to ensure understanding. One of the authors analyzed the interviews using a selective coding method of pre-determined codes that aligned with the interview guide. A code book was developed and discussed with another author. All interviews were transcribed, verbatim, from the audio recordings. After data were transcribed, each interview was hand coded and analyzed using predetermined codes and identification of emergent themes by one of the authors. After analysis was completed, findings were disseminated back to participants to ensure that findings were valid.

RESULTS

The main themes of the interviews included: 1) perception of CAB roles and the need for utilization, 2) Center challenges, and 3) CAB member knowledge and communication.

Perceived Role of CAB members and Need for Utilization

Interview questions assessed what CAB members perceived their role(s) to be within CEH. The majority of responses fell into two categories. The first, acting as a bridge between Moffitt Cancer Center and the community as a whole, was a consistent theme that emerged from the

interviews. Often the interviewer would clarify, Moffitt as being a part of CEH, to which respondents would then acknowledge they (Moffitt and CEH) are "one in the same". Second, CAB members perceived one of their main, explicit roles as acting as a liaison for Moffitt to their specific respective communities. Participants described a variety of tasks of the CAB including:

> *"In essence it is designed to keep CEH connected to the many, many layers of the community, so that community at the grassroots level in particular, like what I would represent and others that I know that are involved, sort of understand the significance of this work"*

Along with the perception of their role in CEH, another issue impacting CAB members was their perceived underutilization within CEH. Almost all of the participants stated that either they had unique skills, or they knew of other members who had skills that could assist and/or enhance CEH, and yet, these were not being tapped by CEH. Every participant had at least one suggestion on how CAB member skills could be enhanced within CEH. Recommendations made by CAB members included needing to have the board in the community more, adding community members into the overall process of CEH, and having an online community calendar accessible to CEH, CAB, and the community.

Challenges for the CAB

Specific interview questions were tailored to ascertain what CAB members felt were challenges for the CAB as whole, as well as for each member specifically. Most participants described challenges related to clarity of the CAB purpose, tasks, and outcomes. Regarding the purpose of the CAB, one participant stated:

> "*I think they are working toward it. I…I, you know, I'd be the first to say that there is a long ways to go. But, with two years under their belt I think that they're….they're trying, they're working towards that." "We are now beginning to see what our function is…you know, what the goal is is (sic) a little clearer"*

As for clarity of tasks, respondents highlighted the ambiguity they have (or had) experienced surrounding the role of CAB:

> *"It's been like trial and error as I've gone along…we are laying groundwork for how we're going to do things at the center…..we knew what the grant required but it did not seem as though there were any particular policies in place [within CEH]"*

Knowledge of CEH Cores

Overwhelmingly, among participants there was limited, if any, knowledge of the CEH Cores, the Cores' individual roles within CEH, and how CAB members should be interacting each of with the Cores. Only one of the CAB members was able to name the five Cores. Additionally, participants described lacking necessary interactions between the CAB and all five CEH cores.

> *"I don't feel closely connected….there could be a little more*

communication, a little more of something to bring us together. I'm a part of Community Education and Outreach but the others; I don't feel like I have any connection to. If you asked me what they do, I have no idea"

Of all the cores, the Community Engagement and Outreach Core (CEOC) resoundingly was thought to be the best in communicating its role with the CAB. Mostly this was due to the level and intensity of communication between the CAB and CEOC, which given the common community focus of both was unsurprising. CAB members interacted with CEOC members on a regular basis, actively participated in CEOC activities including writing grants, running community events, and regularly attending CEOC meetings.

"…they're asking for our input. I would just like to, again, hear that from the other cores. I don't know exactly what they're contributing to CEH. What specifically are they doing?"

Communication between CEH and the CAB

Overall communication methods, frequency, and intensity appeared to be at levels that were deemed appropriate by the CAB. Communication methods included weekly email updates, monthly conference call and in-person meetings, and to some degree, website postings. Cores made their meeting, presentation, and event dates available and encouraged CAB members to attend. Frequency of attendance depended on the number of meetings and events, but also included weekly emails and monthly meetings. The intensity of the level of communication depended upon the degree to which the CAB was asked to participate. For most things, they were simply invited to listen and provide insight in a brief encounter. For others, they may have been requested as a speaker or active participant, requiring more time and effort.

However, CAB members expressed a need for improvement in communication between all five cores in CEH and the CAB. Likewise, communication between CEH and the community was an area that warranted additional attention.

"I don't have a fair picture of what the CEH is doing outside of our own CAB meetings...I don't feel like I have a strong grasp of what the Center for Equal Health is doing in the community. I've seen flyers, gift bags, I know what the mission is, but actually do physically doing in the community, I would be really hard pressed to be able to share that with somebody"

DISCUSSION

This study was an opportunity to further explore how CAB members perceived their role within CEH and how, if necessary, to enhance collaboration. The original intent of this study was to report the evaluation of the status of the relationship of the CAB and CEH and to identify potential solutions to enhance the collaborative relationships and communication. At the time of this evaluation, the feedback opportunities for CAB members were primarily unstructured and informal. The CEH website did contain a feedback form specifically for CAB members, but had not been regularly utilized. Determining communication avenues within organizations is an important, but often overlooked aspect (Cargo, Delormier, Levesque, Horn-Miller, McComber, & Macaulay, 2008).

Regarding challenges of the CAB, participants described those most closely related to clarity of purpose, tasks, and outcomes. Overall there was a collective sense of not clearly understanding the purpose of the CAB. Participants would state that at the onset of CEH, there was even more vagueness associated with what the CAB was designed to do, how it should go about its activities, and how they would know if what they were doing was effective. Members did note that things have gotten better and many participants stated they felt CEH was actively trying to clarify the role of the CAB throughout this process. Challenges related to the need for clarity concerning purpose, tasks, and expected results of CAB members involved has been well-documented (Becker, Israel, & Allen, 2005; Israel, Lichtenstein, Lantz, McGranaghan, Allen, & Guzman, 2001; Kreztmann & McKnight, 1993; McKnight & Kreztmann, 1996; Newman et al., 2011; Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009). To attenuate these challenges it is recommended that roles and responsibilities are decided through consensus and delineated up front (Israel, Lichtenstein, Lantz, McGranaghan, Allen, & Guzman, 2001; Kreztmann & McKnight, 1993; McKnight & Kreztmann, 1996; Newman et al., 2011; Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009). Following the completion of the CAB interviews, further actions were completed by CEH to address challenges. Some of these included acknowledging the complexity of the CAB, its multiple roles, and clearly defining its purpose within CEH as facilitating bi-directional communication between CEH and the community. CAB members proposed developing a new member manual with details of CEH and the core responsibilities, as well as a Community Action Plan with talking points for when they represented CEH in the community. To learn more about the cores and to act as a "CEH ambassador," CAB members selected cores based on their individual interests, attended core meetings to learn of their work, and then reported back to the overall CAB, as well as shared insight with the community at large.

The most consistent theme throughout the interviews was the limited knowledge about other CEH cores, what each was responsible for, and how the CAB was to interact with each. However, the CEOC was known by all of the participants, as was its role within CEH, with the CAB and with the community. Participants overwhelmingly stated that the CEOC had the best communication, was the most regular with providing updates, and was known for making CAB members feel a part of CEH. The fact that CAB members felt the CEOC was the most engaging is not surprising as the intent of the CEOC was to strengthen, enhance and expand meaningful community-academic partnerships that positively impacted health disparities through innovative community awareness and outreach activities. In fact the relationship that existed between the CAB and the CEOC was an excellent representation of *how* communication between a CAB and other aspect of an organization should be conducted (Becker, Israel & Allen, 2005).

A suggestion made by participants to improve understanding of the other cores, was to hold a retreat in order to get everyone together. Additionally, it was thought that an annual retreat would serve as a venue for enhancing communication within CEH. Commonly found in organizations that incorporate a CAB, retreats are an effective mechanism for increasing interactions, communication, and engaging members (Abbajay, 2014). CEH did incorporate feedback to hold an annual retreat for all CEH members whereby individuals from cores and the CAB were able to collaborate in determining next steps for CEH and roles and responsibility for the CAB. During the retreat, several points from the evaluation were addressed. Primarily as a strategy to enhance the cross-core communication, each core began providing updates at the Executive Committee meetings. These meetings provided an opportunity for CAB members to share their thoughts and expertise, as well as inform the Executive Committee on issues from a community perspective.

Finally, utilization of the CAB members was an area that all participants felt needed improvement. Each participant provided excellent suggestions for enhancing and integrating the skill sets of CAB members. As documented by Kretzmann & McKnight (1993) and McKnight & Kretzmann (1996) the recommendations provided by CEH CAB members of conducting asset mapping and allowing the CAB to lead select CEH activities and meetings are all common tools used to highlight skills of CAB members.

CONCLUSION

In response to the most pressing CAB member feedback-- to increase co-leader presence in the community, to add community members into all processes of CEH, and to develop an online community calendar-- CEH created a position for a cross-core coordinator who was in charge of facilitating communication throughout the cores, including the CAB. Additional changes resulted in each core having at least one CAB representative who attended core meetings, and reported back to the CAB to ensure information was being disseminated. A CAB membership subcommittee was also created with the purpose of developing an orientation package for new CAB members. Talking points, in a question and answer format, were compiled to describe the center's overall mission, purpose, structure, activities, and how it was created and funded. It was anticipated that the orientation packet would reduce any ambiguity that may surround the purpose of the center.

Limitations

No study is without limitations. CAB member recruitment and participation may have been influenced by the timing of the study and CAB member attrition, influencing how many people were able to participate and who was able to participate. CAB members may have perceived the interviews as a personal evaluation instead of a process evaluation of collaboration and communication between CEH and the overall CAB; thus leading participants to be less open or less likely to share their thoughts and recommendations. Lastly, the CEOC was the core that led this study and evaluated the results. To address any potential bias all findings were validated by participants and shared with the remaining cores.

Lessons Learned

The purpose of this study was to assess the CAB relationship with that of the CEH. As such, the authors encourage others to learn from these results. Organizations in the early phases of developing a CAB need to consider the importance of integrating the CAB within the existing organization from the very beginning (Becker, Israel, & Allen, 2005; Israel, Lichtenstein, Lantz, McGranaghan, Allen, & Guzman, 2001; Kreztmann & McKnight, 1993; McKnight & Kreztmann, 1996; Newman et al., 2011; Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009). The process should include: carefully identifying potential CAB members, utilizing their strengths, and capitalizing on existing community networks at the beginning of the process to ensure a sustainable community-academic partnership. As described in Newman et al (2011) the development of a CAB must ensure that members will be actively integrated throughout the process, their feedback heard and assimilated, and their strengths utilized as necessary. If CAB member roles and responsibilities are clearly laid out, the overall organization and purpose of integrating a CAB will be more effective (Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009). Understanding that putting together, utilizing and integrating the skills of CAB members is a complex process that takes time, effort, and cannot simply be "something to cross off a to-do list" (Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009, n.p.).

Furthermore, to establish and maintain a viable community-academic partnership, it is critical to evaluate the overall success of the program. Schulz, Israel, and Lantz (2003) describe process analysis as critical to a comprehensive evaluation of a community based program. Ongoing evaluation of the development of the CAB is necessary, from who will be involved to what their roles and tasks will be, to how the process is going (Cargo, Delormier, Levesque, Horn-Miller, McComber, & Macaulay, 2008). Furthermore, evaluation involving community members should inherently include participatory aspects. As such, the use of collaborative or empowerment evaluation techniques are recommended (Rodriguez-Campos & Rincones-Gómez, 2012).

Lastly, the aim of CEH was to work toward reducing and eliminating cancer health disparities among minority and undeserved communities in the state of Florida. By integration and utilization of an effectively functioning CAB, the CEH was able to actively work within diverse local communities to strive for health equity. Knowledge and expertise of CAB members pertaining to local organizations, historical events, and abilities to bridge professionals with community lay persons was paramount for the project's success. Using information from the evaluation of CAB member perspectives only strengthen the CEH's ability to work within the local communities and provided vital information necessary for clarifying and enhancing efforts of the CEH.

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